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The Development and Preliminary Evaluation of the Cancer Peer Support Scale in Adolescents Living with Cancer

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Key Points

- Adolescents living with cancer have unmet psychosocial needs which are strongly related to their levels of psychological distress.
- Peer support is a salient need, associated with positive outcomes for adolescents living with cancer and lower levels of psychological distress.
- We developed a brief 11-item Cancer Peer Support Scale (CaPSS) to assess the quality of peer support experienced by adolescents living with cancer.
- Our study assessed the psychometric properties, validity, and reliability of the CaPSS.
- The CaPSS is a valid and reliable peer support measure for adolescents living with cancer and can be used as an outcome measure to assess peer support.

The Development and Preliminary Evaluation of the Cancer Peer Support Scale in Adolescents Living with Cancer

Adolescents (aged 12 - 18) living with cancer[†] have many unmet needs which are related to their levels of psychological distress [1]. Both cancer patients [2] and adolescents living with a family member with cancer [3] frequently have a need for peer support [1, 3, 4]. For our purposes, the term 'peer support' refers to the support (e.g., social and emotional) one receives from other adolescents who have a cancer experience[‡]. For adolescent and young adult cancer patients, peer support is ranked as more important than support from family members [2].

For adolescents living with cancer, peer support is developmentally appropriate and associated with positive outcomes including better adjustment to cancer, less psychological distress, and enhanced coping strategies and interpersonal relationships [1, 5]. By understanding the degree to which adolescents living with cancer feel supported by their peers, we can better identify and respond to those adolescents who report feeling isolated and alone.

To our knowledge, prior research has not specifically assessed the unique experience and role of peer support between adolescents who have cancer experiences. Given the importance of this construct, we developed the Cancer Peer Support Scale (CaPSS). Our study aims to provide a preliminary evaluation of the psychometric properties, validity, and reliability of the CaPSS.

[†] In this paper, the term 'living with cancer' refers to adolescents who have cancer, survived cancer, have a family member living with cancer, or have experienced the death of a family member from cancer.

[‡] cancer experience includes other adolescents who have been diagnosed with cancer, have had a parent, brother, or sister diagnosed with cancer, or have experienced the death of a family member from cancer.

Method

Participants

Adolescents who were attending a weekend support program provided by CanTeen[§] were invited to participate in the research study. Parental permission/consent and participant assent/consent were obtained. The University of Sydney ethics committee approved the study (Project No.: 2017/104).

CanTeen approached 191 adolescents to participate in the research; 153 agreed (64.7% female; M_{age} = 15.0, SD_{age} = 1.6, *Range* = 11.7 – 18.0). Participants belonged to the following cancer experience categories; patients (15.7%), siblings (14.4%), offspring (38.6%), bereaved sibling (2.0%), or bereaved offspring (25.5%)[**]. A list-wise exclusion was employed for five missing data points.

CaPSS

The following process was used when constructing the CaPSS items; review of the theoretical frameworks of peer support [6, 7]; identification of common factors within current peer support measures (e.g., item content was related to the quality of relationship, trust, general support; reciprocity, and shared experience) [7, 8]; development of items by two researchers (PP & EKD); assessment of the content and face validity of the items by a panel of four clinical experts (PP, EKD, BZ, & DS) with experience in adolescent and young adult psycho-oncology research and/or clinical practice, critique and finalisation of items by the expert panel.

[§] CanTeen is the Australian organisation for young people living with cancer.

The scale contained 11-items with the following sentence stem "*When I think about my interactions with young people who have been diagnosed with cancer or have had a parent, brother or sister with cancer I feel…*" (see Table 1 for all items). Each statement was rated on a five-point Likert scale (i.e., none of the time, a little of the time, some of the time, most of the time, and all of the time). To provide concurrent validity, the CaPSS total score was correlated with the Kessler 10 (K10) psychological distress scale [9].

[TABLE 1]

Statistical analysis

Item response theory (IRT) using *R* (mirt [10]) assessed the underlying factor structure of the CaPSS. IRT assesses if a scale is valid and reliable; and explains the relationship between the latent variable (θ; peer support) and item responses, the psychometric properties of individual items, and participant responses. A two-parameter graded response model estimated item discrimination *(a)* and item difficulty (*b*). Information functions determined how well the items captured those who were low and high on the latent variable. Category probability curves determined the probability of selecting each response category for different values of the latent variable. Item fit was assessed by observing the chi-squared test, factor loadings, and communalities (h^2). Cronbach's alpha (α) measured internal consistency and Pearson bivariate correlations measured the relationship between the CaPSS and the K10.

[**] A one-way ANOVA showed that the CaPSS scores did not differ between the cancer experience categories

Results

The mean and standard deviation scores for each item are given in Table 1. The IRT analysis (Table 1) provided a single factor solution for the CaPSS which accounted for 60.2% of the variance in the underlying factor. Cronbach's alpha showed an acceptable level of internal consistency (α = .88).

The response structure differed slightly between items. In Figure 1, the category probability curves show that all items perform well. However, the probability of selecting a '*little of the time'* is not very strong and only dominates in a small region of the latent variable for most items and is very weak for item 11.

[FIGURE 1]

Table 1 shows that the discrimination parameters are similar between most items. With all items displaying high to very high discriminatory ability, except for item 11, which showed moderate levels.

Each item appears to be capturing information at the lower end of the latent variable (i.e., those experiencing strong peer support) with little difference between items. This suggests that the items might not be capturing respondents experiencing low levels of peer support or our sample includes adolescents who are already experiencing high levels of peer support.

Concurrent Validity

There was a significant negative correlation between scores on the CaPSS and the K10, r = -.28, p < .001. This provides some evidence that the CaPSS is a valid measure, and

shows that participants who have higher perceptions of peer support also have lower psychological distress scores.

Item removal

Item 11 was removed[§§] from the questionnaire due to showing a low factor loading, with only 30% of the variance explained by the latent variable. After removal, Cronbach's alpha slightly improved (α = .89), indicating scale adequacy.

Discussion

The results suggest the CaPSS is a reliable and valid brief measure of peer support for adolescents living with cancer. Our results strengthen previous findings that social support is associated with positive outcomes for adolescents living with cancer [5], with those reporting higher levels of peer support tending to have lower psychological distress.

Peer support between adolescents living with cancer has not been well measured previously in the literature; the CaPSS now allows for this construct to be measured with greater accuracy. However, our concern is that the CaPSS may not be capturing participants experiencing low levels of peer support. Alternatively, this could be explained by existing high levels of support amongst our sample. Further validation using a more diverse sample, and assessing discriminant, predictive, and concurrent validity will confirm if the scale accurately captures adolescents with low and high levels of peer support.

The ability to identify how well supported adolescents perceive themselves to be by their peers allows a more accurate measure of how effective programs are at improving peer support for adolescents living with cancer. By measuring and understanding the levels of peer

support experienced by adolescents impacted by cancer, the appropriate support can be provided with the potential to improve their overall wellbeing.

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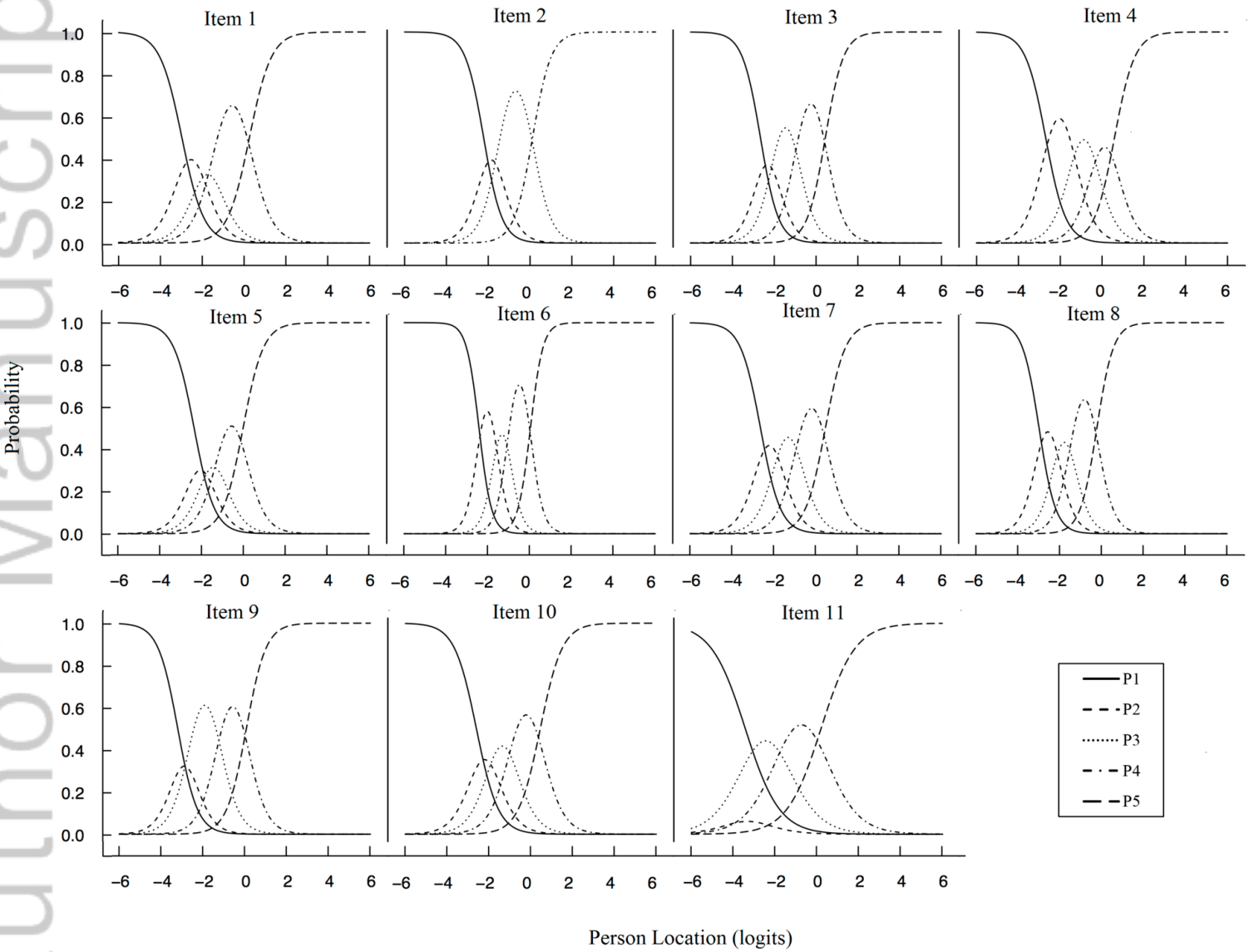
Table 1

The mean and standard deviation for each CaPSS item and the results of the IRT analysis.

Item	*M*	*SD*	X^2	*p*	*a*	Location parameters *b1*	*b2*	*b3*	*b4*	Factor Loading	h^2
1. I have been accepted for who I am	4.18	0.89	14.17	.362	1.90	5.64	3.97	2.62	-0.49	.74	.55
2. I have been respected	4.31	0.75	14.26	.284	2.26	5.02	3.36	-0.27	—	.80	.64
3. I have been understood	4.05	0.89	10.68	.637	2.31	6.15	4.59	2.14	-1.03	.81	.65
4. I was able to be open and honest about how I felt	3.74	1.09	15.94	.819	2.07	5.58	2.87	0.73	-1.23	.77	.60
5. I wasn't judged	4.16	1.05	20.92	.341	2.05	4.86	3.62	2.31	0.06	.77	.59
6. I was listened to	4.20	0.94	14.42	.211	3.34	8.09	5.44	3.39	-0.12	.89	.79
7. I was able to talk about things that were important to me	3.98	0.98	9.17	.906	2.09	5.52	3.74	1.76	-0.97	.78	.60
8. I was supported	4.41	0.81	9.22	.602	2.52	7.54	5.44	3.59	0.58	.83	.69
9. I was able to support them	4.28	0.81	14.52	.411	2.13	6.83	5.49	2.65	-0.15	.78	.61
10. They understood how cancer affected my life	4.00	1.00	23.40	.104	1.91	4.96	3.48	1.70	-0.86	.75	.56
11. I understood how cancer affected their life	4.22	0.89	10.45	.842	1.23	4.20	3.95	2.05	-0.24	.58	.34

n = 148



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